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Simon Phillips  
Department of Health  
Room 403, Wellington House  
133 -155 Waterloo Road  
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18 May 2011

Dear Simon

### **8-05 (b)/2010 National Cancer Survivorship Initiative – patient reported outcome survey of cancer survivors**

Thank you for your application for support under section 251 of the NHS Act 2006 to process patient identifiable information without consent. This application was considered by the Ethics and Confidentiality Committee at its meeting on 01 December 2010.

#### **Context**

This application from the Department of Health (acting as sponsor) and Quality Health (the implementation provider) sought support to cover the pilot phase of a proposed national survey of cancer survivors, which is intended to last up until 30 June 2011.

**Update: due to slippages in timetables, it has been noted that following notification on 17 May 2011, that the survey will be completed by September 2011.**

The purpose of this activity was to aim to improve understanding of quality of life outcomes for cancer survivors and was intended to support the DH National Cancer Survivorship Initiative (NCSI). The activity would build upon the current national Cancer Patient Experience Survey Programme (CPESP) 2010 which focuses on the experience of care of cancer patients.

Section 251 support was sought to enable the legitimate transfer of patient data from the Cancer Registries to Quality Health, and for Quality Health to liaise with cancer centres so that patient questionnaires would be sent to patients under cover of appropriate cancer centre letter headed paper. Support was also required to enable a sample to be identified from the cancer registries. To carry out the activity, Quality Health would require access to name, address, sex, ethnic group, year of birth, NHS number, ICD10 code, speciality code, date of diagnosis, and Trust NACS code for most recent treatment spell.

#### **Outcome**

The letter dated 07 December 2010 set out the Committee's rationale and decision for its recommendation of provisional support, subject to a number of clarifications and conditions of approval. A response was subsequently provided providing copies of requested documentation and further explanation around the clarification areas.

In particular, Members debated the response to the information being sent on GP headed paper, and on balance and in this specific instance, agreed that this would not be feasible.

As all aspects have been satisfactorily addressed, this letter provides confirmation of your final approval, and our Register of approved applications will shortly be updated to include this application.

If you have any queries regarding the outcome of this letter please do not hesitate to contact the NIGB Office on 020 7633 7052. Email queries should be sent to [eccapplications@nhs.net](mailto:eccapplications@nhs.net).

Yours sincerely

Natasha Dunkley  
**NIGB Approvals Manager**

### **Ethics and Confidentiality Committee Standard conditions of approval**

The support provided under section 251 is subject to the following standard conditions.

The applicant will ensure that:

1. The requested patient identifiable information is only used for the purpose(s) set out in the application.
2. Confidentiality is preserved and that there is no disclosure of information in aggregate or patient level form that may inferentially identify a person, nor will any attempt be made to identify individuals, households or organisations in the data.
3. Requirements of the Statistics and Registration Services Act 2007 are adhered to regarding publication when relevant.
4. All staff with access to patient identifiable information have contractual obligations of confidentiality, enforceable through disciplinary procedures.
5. All staff with access to patient identifiable information have received appropriate ongoing training to ensure they are aware of their responsibilities.
6. Activities are consistent with the Data Protection Act 1998.
7. Audit of data processing by a designated agent of the Secretary of State is facilitated and supported.
8. The wishes of people who have withheld or withdrawn their consent are respected.
9. The NIGB Office is notified of any significant changes which impact on the approval of the application.
10. An annual review to be provided no later than 12 months from date of your final approval letter